

Research & Training Center in Service Coordination

CFDA # 84.324L



University of Connecticut
Indiana University
University of North Carolina, Chapel Hill
Federation of Children with Special Needs

Presentation Overview

- Review RFP requirements
- Project objectives
- Operating principles
- Description of our project
- Synthesis of project findings
- Implications for the field
- Next steps

US Dept. of Education RFP

- Research & Training Center to:
 - Carry out a coordinated, integrated and advanced research program in service coordination.
 - Provide training in service coordination for graduate preservice and inservice practitioners, trainers and researchers.

Service Coordinator Description Federal Register

a) General.

(1) As used in this part, except in §303.12(d)(11), service coordination means the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the state's early intervention program.

(2) Each child eligible under this part and the child's family must be provided with one service coordinator who is responsible for:

- Coordinating all services across agency lines; and
- Serving as a single point of contact in helping parents to obtain the services and assistance they need.

(3) Service coordination is an active, ongoing process that involves:

- Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan;
- Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) so that the child's needs are being provided;
- Facilitating the timely delivery of available services; and
- Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.

Service Coordination Activities

- Coordinating the performance of evaluations and assessments;
- Facilitating and participating in the development, review, and evaluation of individualized family service plans;
- Assisting families in identifying available service providers;
- Coordinating and monitoring the delivery of available services;

Service Coordination Activities (cont.)

- Informing families of the availability of advocacy services;
- Coordinating with medical and health providers; and
- Facilitating the development of a transition plan to preschool services, if appropriate.

Service Coordinator Employment Assignment

Service coordinators may be employed or assigned in any way that is permitted under state law, so long as it is consistent with the requirements of this part.

- (2) A State's policies and procedures for implementing the statewide system of early intervention services must be designed and implemented to ensure that service coordinators are able to effectively carry out on an interagency basis the functions and services listed under paragraphs (a) and (b) of this section.

- Service coordinators must be persons who, consistent with §303.344(g), have demonstrated knowledge and understanding about:
 - Infants and toddlers who are eligible under this part;
 - Part C of the act and the regulations of this part; and
 - The nature and scope of services available under the state's early intervention program, the system of payments for services in the state, and other pertinent information.

Project Objectives

- Describe current models of service coordination.
- Identify outcomes of effective service coordination.
- Identify recommended practices.
- Measure practices & outcomes of effective service coordination.
- Develop & validate training models.
- Disseminate information across stakeholder groups.

Principles

- Collaborative model of integrated activities.
- Families are an integral component of our project.
- Stakeholders contribute to all phases of the center activities.
- Interdisciplinary efforts focus on system-wide change between and among groups.

Principles (cont.)

- Research & training are interdependent and focused on the same outcome.
- Research focuses on applied problems in a rigorous manner.
- Training and dissemination will promote adoption of solutions.

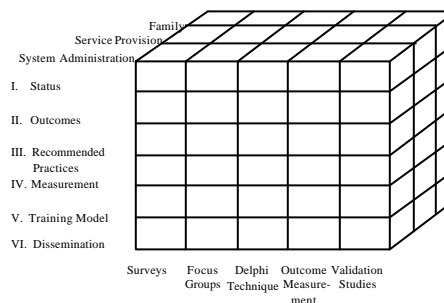
This is a COLLABORATIVE PROJECT

- Four primary sites
 - University of Connecticut
 - University of North Carolina-Chapel Hill
 - Indiana University
 - Federation for Children with Special Needs: Massachusetts

"You cannot solve a problem from within the same consciousness that created the problem...you must think anew."
Einstein



Center Framework



Objective 1

Describe current models of service coordination.

What we did:

We conducted a series of surveys to describe and define service coordination.

1.1 Part C Survey

- Purpose:
 - To describe current status of Part C service coordination models.
- Sample:
 - ALL Part C coordinators in 57 states & territories.

Part C Survey Findings

- 39 Part C coordinators reported lack of uniformity in how service coordination was provided in their state.
- 36 states used regional approach.
- Service coordinator case loads:
 - Ranged from 9 – 70 with mean = 38.
- 17 states were changing service coordination models.

1.2 Curricula Survey

- Purpose:
 - To identify training practices & competencies for service coordinators.
- Sample:
 - Training personnel from 55 states + territories.

Curricula Survey Findings

- Information was obtained from 55 states & territories.
- Average length of training in 37 states:
 - 2 –3 days.
- 49% (n= 27) states mandated service coordination training.
- 47% (n=26) states were in process of developing service coordination curricula.

1.3 Parent Leader Survey

- Purpose:
 - To provide descriptions of families' perceptions of their state's model of service coordination.
- Sample:
 - 319 parent leaders in 50 states & DC

Parent Leader Findings

- 26% (n=83) of families did not learn who their service coordinator was until after the IFSP.
- 36% (n=118) of families felt service coordination was very helpful.
- 38% (n=121) of parents believed service coordination was very effective in developing IFSP's that were responsive to child and family needs.

1.4 Parent ICC Phone Survey

- Purpose:
 - To determine participant's perceptions of service coordination models and practices in their states.
- Sample:
 - Parent leaders in each of 50 states who serve on ICC boards.

Parent ICC Findings

- 60% (n= 30) of ICC parent representatives considered themselves familiar with federal regulations.
- 64% (n=32) said ICC's were familiar with federal regulations.
- 48% (n=24) were unsure if state had specific model for service coordination

Objective 2

Identify outcomes of effective service coordination.

What we did:

We determined outcomes of effective service coordination across four groups of stakeholders.

2.1 Focus Groups

- Purpose:
 - To identify OUTCOMES of service coordination that are important to families
- "If service coordination was of the highest quality for children, families, and systems, how would you know it?"

Focus Groups

- Sample:
 - Parents, Service Providers, Service Coordinators, Program Administrators, Physicians, Childcare Providers
 - 47 focus groups consisting of 397 participants in the 6 stakeholder groups
- Yielded 250 outcomes of high quality service coordination.
- These outcomes were used to develop the Delphi survey instruments.

2.2 Delphi Study

- Purpose:
 - To identify agreed upon outcomes of service coordination
- Sample:
 - Parents, Service Providers, Service Coordinators, Program Administrators, Physicians, Childcare Providers
 - In 4 states

Outcome Delphi Distribution

Parent	Service Provider	Service Coord.	Program Admin.	Physician	Childcare Provider
(Indiana)					
80	22	144	86	9	54

Total of 395 surveys were distributed

Delphi (Outcomes) Data Reduction

- Round I :
 - Frequency distributions generated for survey returns
 - Retained outcomes that 355% rated as "extremely desirable"
 - 250 outcomes reduced to 75
- Round II :
 - Retained outcomes that 375%
 - Outcomes represented all stakeholder groups and states

Results: 8 Outcomes

- Children and families receive appropriate supports and services that meet their individual needs.
- Children reach their full potential.
- Children are healthy.
- Children's development is enhanced.
- Children have successful transitions.
- Families are involved in decision making.
- Families are informed about resources and services.
- People work together as a team.

2.3 Parent/Practitioner Survey

- Purpose:
 - To collect additional data on outcomes of effective service coordination.
 - To determine if desirable outcomes of service coordination could be distinguished from outcomes of natural environments and/or early intervention system.

2.3 Parent/Practitioner Survey (cont.)

- Sample:
 - 879 early intervention program practitioners and directors (59%) and parents of children with disabilities (41%) in 48 states.

Parent/Practitioner Survey Findings

- Certain categories of outcomes were more likely to be judged as the desired benefits of a specific Part C service.
- Differences were detected in how outcomes were ranked between categories of service coordination, natural environments and early intervention system.

Parent/Practitioner Survey Findings (cont.)

- 5 outcomes were identified as desired benefits of service coordination:
 - System coordination
 - Information and referral
 - Family support and resources
 - Family centered practices
 - Teaming

Parent/Practitioner Survey Findings (cont.)

- Outcomes were valued for all three categories:
 - Family satisfaction
 - Improved family quality of life

Objective 3

Identify recommended practices

What we did:

We determined practices related to effective service coordination.

3.1 Focus Groups

- Purpose:
 - To identify PRACTICES that lead to outcomes of high quality service coordination.

"What practices support the identified eight outcomes of services coordination?"

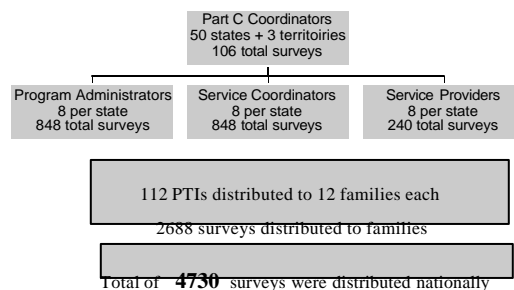
Focus Groups

- Sample:
 - Parents, Service Providers, Service Coordinators, Program Administrators.
 - 39 focus groups consisting of 275 participants in the 4 stakeholder groups:
- Yielded 2000+ practices that lead to outcomes of high quality service coordination.
- These practices were used to develop the Delphi survey instruments.

3.2 Delphi Study

- Purpose:
 - To identify practices that lead to the 8 outcomes of high quality service coordination.
- Sample:
 - Parents, Service Providers, Service Coordinators, and Program Administrators in 53 states/territories.

Practice Delphi Distribution



Delphi Responses

- 27.9% returned
- Representation from 41 states/territories

Families	Service Provider	Service Coord	Program Admin	Part C Coord
322	260	369	317	50

Continuation of Delphi Process

- 5 outcome statements have been refined from the original 8 outcomes by consensus of Project Investigators.
 - 1. Families are informed about resources and services.
 - 2. Families are involved in decision making.
 - 3. Children and families receive appropriate supports and services that meet their individual needs.
 - 4. Children's health and development is enhanced.
 - 5. Children have successful transitions.

3.4 Parent Survey

- Purpose:
 - To explore families' experiences with service coordination practices, early intervention practices and natural environments practices.
- Sample:
 - 5,100 parents of children receiving early interventions services in 50 US states and DC.
- Distributed during November 2002-February 2003.

Objective 4

Measure practices & outcomes of effective service coordination

What we did:

We conducted interviews with family and family's service coordinator.

4.1 Family Interviews

- Purpose:
 - To determine outcomes of service coordination that were most important to each family.
 - To identify practices that resulted in the desired outcomes.
- Sample:
 - 100 families in 4 states (n=80)
 - Stratified across ethnicity, location, income, disability, language

Family Demographics

Location	Frequency	Percent
Urban	32	40.0
Suburban	29	36.2
Rural	19	23.8
Ethnicity		
Black	19	23.8
White	34	42.5
Latino	10	12.5
Other	17	21.2

Family Demographics (cont.)

Income	Frequency	Percent
Low	33	42.3
Not low	45	57.7
Child's Age		
0-1	25	31.3
1-2	25	31.3
2-3	30	37.4
Needs		
Mild	35	44.3
Moderate	25	31.6
Complex	19	24.1

4.2 Service Coordinator Interviews

■ Purpose:

- To measure service coordinators' perceptions of outcomes that were important to each family.
- To identify practices that resulted in outcomes of effective service coordination.

■ Sample:

- 100 service coordinators (of families interviewed) were interviewed by telephone (n=80).

Service Coordinator Demographics

Employment	Frequency	Percent
Part time	27	41.5
Full time	38	58.5
Experience (years)		
0-1	12	18.5
1.1-5	29	44.6
5.1-10	17	26.1
10.1-15	4	6.2
15.1-20	2	3.1
20.1+	1	1.5

Service Coordinator Demographics

■ Experience

- Minimum: 0.25 years
- Maximum: 32.0 years
- Mean: 5.34 years

■ Caseload

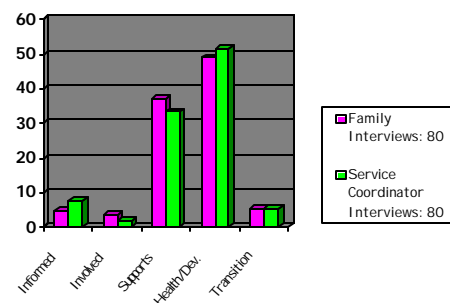
- Minimum: 1 case
- Maximum: 104 cases
- Mean: 20.6 cases

Interview Findings

■ Identified

- Outcomes important to families.
- Who assisted the family in achieving the outcomes.
- How service coordination helped achieve the outcomes.
- How long it took to achieve the outcome.

"What Would You Like to See for Your Child/ Family?"

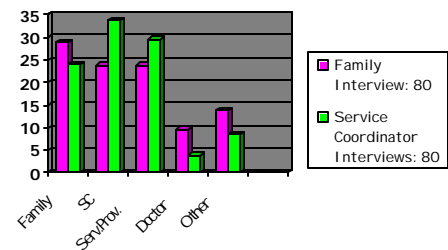


Percent Agreement Between Families & Service Coordinators

"What would you like to see for your child and family?"

- Range:
11.1 – 100.0
- Mean Percent agreement:
54.5
- Standard Deviation:
18.2

"Who Helped Make this Happen?"



Percent Agreement between Families & Service Coordinators

"Who Helped Make this Happen?"

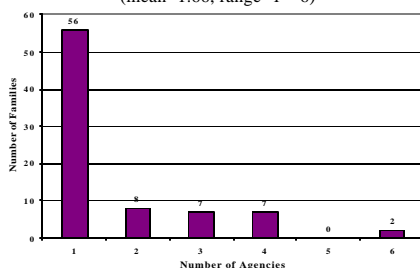
- Range:
8.3 - 77.8
- Mean Percent agreement:
46.1
- Standard Deviation:
15.0

I FSP Analysis

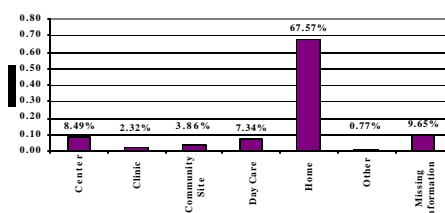
- 80 I FSP's were available
- 60% of I FSP's had missing data
- I FSP's were reviewed for
 - Number of agencies involved, team members, types of services, location of services
 - Outcomes
 - to allow comparison between interviews and documentation

I FSP Data Graph Agencies Used by Families

(mean=1.66, range=1 – 6)



I FSP Data Graph Location of Service Provided



Highlights of Project Findings

- Stakeholders are very interested in service coordination and can identify outcomes and practices.
- State systems are complicated and there is a lack of infrastructure and policy guidance.
- There is an absence of service coordination training.
- Family and service providers are seeing things differently in regard to service coordination, outcomes and practices.

Where do we Go from Here?

- Explore different ways of looking at our data
- Develop materials that can be used by service providers
- Conduct new studies

Data Analysis

- Correlational Studies to determine factors that have greatest impact on service coordination.

Develop Materials

- Tool Kit for Early Intervention Providers
- Provide concrete behaviors for service providers that operationalize best practice
- Checklist for Service Coordinators
- Checklist for Parents
 - Identifying Available Services
 - Matching their Needs with Available Services

New Studies

- Descriptions of underrepresented families and families with multiple service agencies
- Measurable indicators
- Validation practices
- Contextual variables that affect service coordination
- Training methodologies

Anticipated Outcomes

- Indicators for five outcomes
- Validated Practices
- Training guides for methodologies
- Toolkits
 - Families
 - Service coordinators
 - Service providers
 - Administrators

Dissemination

- UCE – AJ Pappanikou Center for Disabilities Web Site:
- <http://www.uconnced.org/>
 - Data Reports
 - Newsletters
 - Progress Reports
- Articles
- Presentation